General

Guideline Title

Palliative care for the patient with incurable cancer or advanced disease. Part 3: grief and bereavement.

Bibliographic Source(s)

Medical Services Commission. Palliative care for the patient with incurable cancer or advanced disease. Part 3: grief and bereavement. Victoria (BC): British Columbia Medical Services Commission; 2011 Sep 30. 16 p. [13 references]

Guideline Status

This is the current release of the guideline.

Recommendations

Major Recommendations

Note from the National Guideline Clearinghouse (NGC): The recommendations below are the third in the Medical Services Commission, British Columbia palliative care guidelines series. See the following guidelines for the rest of the series:

- Palliative care for the patient with incurable cancer or advanced disease. Part 1: approach to care
- Palliative care for the patient with incurable cancer or advanced disease. Part 2: pain and symptom management

Grief

A. Assessment of Grief
    - Consider using the distress screening tool (refer to "Screening Tools for Measuring Distress" in Appendix A of the original guideline document) to ascertain the degree of psychosocial, spiritual, and physical distress. This is best given to the patient to be filled out while waiting to be seen. Scores of 5+ on the distress thermometer are significant and the problem checklist provides valuable assessment information.
    - Be aware of the potential desire for hastened death; if present, assess for suicide risk.
    - Focus on personal strengths and coping mechanisms; what has worked in the past?
    - Protective factors/resiliency for a patient or caregiver:
        - Has an internalized belief in his/her own ability to cope effectively.
        - Perceives the need for AND is willing to access social support.
        - Is predisposed to a high level of optimism/positive state of mind.
        - Has spiritual/religious beliefs that assist in coping with the death.

    All of us grieve differently due to age, gender, personal, religious, and cultural differences; enquire regarding cultural and individual

preferences (refer to "Cultural Diversity and Individual Preferences" in Appendix B of the original guideline document) and be aware of age differences (refer to "Children and Death" in Appendix C of the original guideline document).

B. Management of Grief
   a. *Non-pharmacological Management*: The relationship between the physician and the patient is one of the most potent therapeutic tools for assisting patients who are dealing with grief. Reassurance about the normal pattern of grief and a commitment to supporting the patient in an ongoing way is the mainstay of care. It may involve a scheduled follow-up visit as necessary. Within that context, the following aspects of management should be considered.
   Table: Non-pharmaceutical Management of Grief

Acknowledgement of Loss(es)	Use whatever words are appropriate in the context of the relationship with the patient and family. Patient handout: Normal Manifestations of Grief (Patient handout: "Normal Manifestations of Grief" is provided in Appendix D of the original guideline document).
Education	• Normalize responses to loss (e.g., "you are not going crazy"). • Discuss what to expect when grieving.
Lifestyle Management	• Explore what is personally helpful to the patient (e.g., rest, exercise, social connections, spiritual support, home support, compassionate care benefits program).
Resources	Patient handout: Normal Manifestations of Grief (see Appendix D in original guideline document).

   b. *Pharmacological Management*: In general, there is a limited place for pharmacological management in normal grief. The physician must be alert to the possibility of underlying disease and incipient pathologic grief and treat accordingly, but it is unwise to interrupt the normal constituents of grief such as depressed mood, anxiety, insomnia and anger.
   c. *Other Supports*: Other support options are patient and caregiver support groups, on-line support groups, spiritual care and/or faith based communities, and hospice/palliative care programs including volunteer support. Refer for individual counselling when requested and appropriate.

<u>Bereavement</u>

Bereavement includes the period of adjustment following a person's death and it encompasses many elements of grief, including complicated grief. Anticipate/screen for complicated grief reactions and also consider using the "Bereavement Risk Assessment Tool" (refer to Appendix E in the original guideline document) to assess risk.

A. Risk Factors for Complicated Grief in Bereavement
   a. Co-morbidities: mental illness; cognitive impairment; substance abuse.
   b. Concurrent stressors: multiple losses; significant other with life-threatening illness.
   c. Circumstances around the death: received as preventable; sudden, unexpected, traumatic or untimely.
   d. Lack of Supports: social isolation; disenfranchised grief; cultural or language barriers.
   e. Relationships: anger; ambivalence; resentment; insecurity.

B. Assessment of Bereavement (see the "Bereavement Algorithm" in Appendix F of the original guideline document)
   - The following tools may be useful in support of the ongoing physician patient relationship:
     - Issues with different ages, especially children (refer to "Children and Death" in Appendix C of the original guideline document).
     - Bereavement Risk Assessment Tool (refer to Appendix E in the original guideline document).
     - Bereavement Algorithm (refer to Appendix F in original guideline document).
     - Guide to Bereavement Assessment and Support (refer to Appendix G in original guideline document).
     - Caregiver Questionnaire (refer to Appendix H in original guideline document).
   - Timing for assessment of caregivers for bereavement/grief
     - 2–8 weeks: assess for grief related depression (refer to "Distinguishing Grief and Depression" in Appendix I of the original guideline document) and other health issues (e.g., sleep, nutrition)
     - 6 months: assess for complicated grief if not already identified and treated.
   - Criteria for diagnosing complicated grief
     Yearning for the deceased must be experienced at least daily over the past month or to a distressing and disruptive degree, i.e., intense and intrusive thoughts, unusual sleep disturbance, suicidal ideation, and the persistence for at least six months of four of the following eight symptoms:

- Difficulty moving on or reengaging with life
- Numbness/detachment
- Excessive bitterness or anger about the death
- Feeling that life is empty
- A sense that the future holds no meaning without the deceased
- Trouble accepting the death
- Being on edge or agitated
- Difficulty trusting others since the loss; social withdrawal

These symptoms can cause marked dysfunction in social, occupational, self care, or other important domains.

C. Management of Bereavement (refer to the "Bereavement Algorithm" in Appendix F of the original guideline document)

a. *Non-pharmacological Management*

Table: Non-pharmacological Management of Bereavement

At Time of Death (or ASAP there-after)	• Personally contact the bereaved person/family. • Acknowledge the death and reactions including feelings such as guilt, relief, or shock. • Ascertain and address immediate concerns about care, the death, or the funeral. • Arrange for follow-up contact.	
After Death	Self-management	• Provide information about grief, i.e., what to expect and what is helpful (refer to Appendix D - Normal Manifestations of Grief [Patient Handout] in the original guideline document). • Provide information about local resources (e.g., bereavement groups, spiritual/religious supports, grief counsellors) and online resources (refer to Grief and Bereavement Guideline Resource Links [Patient Handout] in Appendix J of the original guideline document). • Share Be Gentle with Yourself (Patient handout; refer to Appendix K in the original guideline document).
	Ongoing care contact	• Within 2 weeks, acknowledge, or contact family. • Contact again at 1-2 months, 6 months, and 11-12 months (anniversary of the death). • Recognize that holidays, birthdays, and wedding anniversaries are tough. • Be aware that the second year can also be difficult.

ASAP, as soon as possible

b. *Pharmacological Management*

85% of grief in bereavement is normal grief, not requiring pharmacological management

Table: Pharmacological Management of Bereavement

Benzodiazepines	• Benzodiazepines have a very limited role in the management of acute grief.
Treating Grief-Related Major Depression: Antidepressants	• Treat grief-related major depression once you are confident it is pathological. • If depression is suspected while a person is acutely grieving, start by recommending regular exercise, counselling, and supports. If symptoms are worse or not improving by 8 weeks post-death, start antidepressant medication (refer to "Depression - Diagnosis and Management" in the NGC summary of the Medical Services Commission, British Columbia guideline Palliative care for the patient with incurable cancer or advanced disease. Part 2: pain and symptom management).
Treating Complicated Grief	• Assess in the context of the person's life, personality, culture, and the nature of the illness/death. • Refer to a bereavement counsellor, psychologist, or psychiatrist who will provide targeted psychotherapy, Complicated Grief Treatment (CGT), in addition to possible pharmacologic management.

Clinical Algorithm(s)

A bereavement algorithm is provided in Appendix F of the original guideline document.

Scope

Disease/Condition(s)

- Incurable cancer
- Advanced cancer
- Grief
- Bereavement

Guideline Category

Counseling

Evaluation

Management

Risk Assessment

Screening

Treatment

Clinical Specialty

Family Practice

Geriatrics

Internal Medicine

Nursing

Psychology

Intended Users

Advanced Practice Nurses

Health Care Providers

Nurses

Other

Physician Assistants

Physicians

Psychologists/Non-physician Behavioral Health Clinicians

Social Workers

Guideline Objective(s)

- To address the needs of adult patients with incurable cancer or advanced disease (but also useful for adults dying of any cause), as well as the needs of their caregivers or family, including children
- To provide information and tools to improve a primary care provider's comfort and skills in dealing with this type of loss

Target Population

- Adult patients with incurable cancer or advanced disease
- Adults dying of any cause
- Caregivers or family, including children, of adults who are dying

Interventions and Practices Considered

Assessment/Diagnosis

1. Screening for level of distress
2. Assessment of suicide risk
3. Assessment of coping mechanisms and patient resiliency
4. Assessment of risk of complicated grief
5. Timing of assessments

Management/Treatment

1. Non-pharmacological management: acknowledgement of loss, education, lifestyle management (e.g., rest, exercise, social connections, spiritual support, home support, compassionate care benefits program), provision of handouts
2. Pharmacological management (e.g., benzodiazepines) in limited situations
3. Other support: patient and caregiver support groups, on-line support groups, spiritual care and/or faith based communities, hospice/palliative care programs
4. Pharmacological treatment of grief-related major depression
5. Referral to a bereavement counsellor, psychologist, or psychiatrist, as appropriate or if requested

Major Outcomes Considered

- Validity and predictive capacity of assessment scales
- Effectiveness of individual coping mechanisms
- Duration of grieving period with pharmacological and non-pharmacological treatment

Methodology

Methods Used to Collect/Select the Evidence

Searches of Electronic Databases

Description of Methods Used to Collect/Select the Evidence

Evidence was obtained through a systematic review of peer-reviewed literature (up to December 2010) using the databases MEDLINE, PubMed, EBSCO, Ovid, and the Cochrane Collaboration's Database for Systematic Reviews. Clinical practice guidelines from other jurisdictions for grief and bereavement were also reviewed (up to December 2010).

Number of Source Documents

Not stated

Methods Used to Assess the Quality and Strength of the Evidence

Not stated

Rating Scheme for the Strength of the Evidence

Not applicable

Methods Used to Analyze the Evidence

Systematic Review

Description of the Methods Used to Analyze the Evidence

Not stated

Methods Used to Formulate the Recommendations

Expert Consensus

Description of Methods Used to Formulate the Recommendations

This is an evidence based clinical guideline for general practitioners including consensus statements when evidence is not available. It is based on scientific evidence current as of the Effective Date.

Rating Scheme for the Strength of the Recommendations

Not applicable

Cost Analysis

A formal cost analysis was not performed and published cost analyses were not reviewed.

Method of Guideline Validation

External Peer Review

Internal Peer Review

Description of Method of Guideline Validation

The guideline was approved by the British Columbia Medical Association and adopted by the Medical Services Commission.

Evidence Supporting the Recommendations

Type of Evidence Supporting the Recommendations

This is an evidence based clinical guideline for general practitioners with consensus statements when evidence is not available. The type of supporting evidence is not specifically stated for each recommendation.

Benefits/Harms of Implementing the Guideline Recommendations

Potential Benefits

Appropriate assessment and management of patients undergoing grief and bereavement

Potential Harms

Not stated

Qualifying Statements

Qualifying Statements

The Clinical Practice Guidelines (the "Guidelines") have been developed by the Guidelines and Protocols Advisory Committee on behalf of the Medical Services Commission (MSC). The Guidelines are intended to give an understanding of a clinical problem and outline one or more preferred approaches to the investigation and management of the problem. The Guidelines are not intended as a substitute for the advice or professional judgment of a health care professional, nor are they intended to be the only approach to the management of clinical problems. The MSC cannot respond to patients or patient advocates requesting advice on issues related to medical conditions. If you need medical advice, please contact a health care professional.

Implementation of the Guideline

Description of Implementation Strategy

An implementation strategy was not provided.

Implementation Tools

Chart Documentation/Checklists/Forms

Clinical Algorithm

Patient Resources

Resources

For information about availability, see the *Availability of Companion Documents* and *Patient Resources* fields below.

Institute of Medicine (IOM) National Healthcare Quality Report Categories

IOM Care Need

End of Life Care

IOM Domain

Effectiveness

Patient-centeredness

Identifying Information and Availability

Bibliographic Source(s)

Medical Services Commission. Palliative care for the patient with incurable cancer or advanced disease. Part 3: grief and bereavement. Victoria (BC): British Columbia Medical Services Commission; 2011 Sep 30. 16 p. [13 references]

Adaptation

Not applicable: The guideline was not adapted from another source.

Date Released

2011 Sep 30

Guideline Developer(s)

Family Practice Oncology Network - Professional Association

Medical Services Commission, British Columbia - State/Local Government Agency [Non-U.S.]

Source(s) of Funding

Medical Services Commission, British Columbia

Guideline Committee

Guidelines and Protocols Advisory Committee

Composition of Group That Authored the Guideline

Not stated

Financial Disclosures/Conflicts of Interest

Not stated

Guideline Status

This is the current release of the guideline.

Guideline Availability

Electronic copies: Available from the British Columbia Ministry of Health Web site .

Availability of Companion Documents

Various screening and assessment tools and guides, a caregiver questionnaire, and information about cultural diversity and individual preferences are available in the appendices to the original guideline document .

Patient Resources

Various patient handouts and guides for recognizing and coping with grief are available in the appendices to the original guideline document .

Please note: This patient information is intended to provide health professionals with information to share with their patients to help them better understand their health and their diagnosed disorders. By providing access to this patient information, it is not the intention of NGC to provide specific medical advice for particular patients. Rather we urge patients and their representatives to review this material and then to consult with a licensed health professional for evaluation of treatment options suitable for them as well as for diagnosis and answers to their personal medical questions. This patient information has been derived and prepared from a guideline for health care professionals included on NGC by the authors or publishers of that original guideline. The patient information is not reviewed by NGC to establish whether or not it accurately reflects the original guideline's content.

NGC Status

This NGC summary was completed by ECRI Institute on January 31, 2013. The information was verified by the guideline developer on March 20, 2013.

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Readers with questions regarding guideline content are directed to contact the guideline developer.